

The Art of Inclusion: Mainstreaming the rights of people with psychosocial disabilities in health and social systems

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Background

- People with psychosocial disabilities* present a particularly marginalised group, with many facing barriers in accessing care¹
- Exacerbated due to poverty, stigma & the invisibility & complex history of disability & mental health.²⁻³
- Limited research on the priorities of people with psychosocial disability from their own perspective within lower middle-income countries.

*Psychosocial disabilities can include complex mental health conditions such as bipolar disorder, schizophrenia, epilepsy and major depressive disorders

Country Context: Liberia

- 16% of the population are thought to live with disabilities.⁴
- The civil war and Ebola epidemic in Liberia weakened the health system and worsened mental health impacts.
- With limited resources for mental healthcare, many individuals with psychosocial disabilities face stigma and discrimination⁵
- Conditions are often unrecognized and untreated.



Aim:

To understand the lived experiences of people with psychosocial disabilities & caregivers through participatory arts-based research and understand service delivery gaps from key informants in Monrovia and Margibi, Liberia

Methods

Working in partnership with research assistants with lived experience: Rev. Bill. S. Jallah and Ms. Kula Dukuly

Data Collection: Participant led arts-based methods



Alt-text: Collage of two female participants and one male participant smiling and holding their illustrations

10 Participatory illustrations with participants with lived experience

9 Caregiver semi-structured interviews

18 Key informant interviews

Co-Analysis



Co-analysis session & thematic analysis with research assistants

Preliminary Findings

Imagery and storytelling led to a creative and reflective process which produced images representing multiple aspects of experiences. Themes included: co-researchers' journey to care, identity creation, impact of war & fragility, barriers in healthcare and participation, stigma, and support, hopes and aspirations.

Journey to Care



Illustration of psychiatric hospital

"I didn't know what was happening to me...I couldn't find any answers to why this was happening to me. They took me everywhere, church, traditional healers, and different hospitals"

(Male participant, 67 years old, bi-polar disorder, Monrovia)

- Moving between faith healers, church, traditional healers and hospital
- Diagnosis
- Barriers to care: lack of medicine, attitude of health workers

Stigma, Violence & Violation of Rights

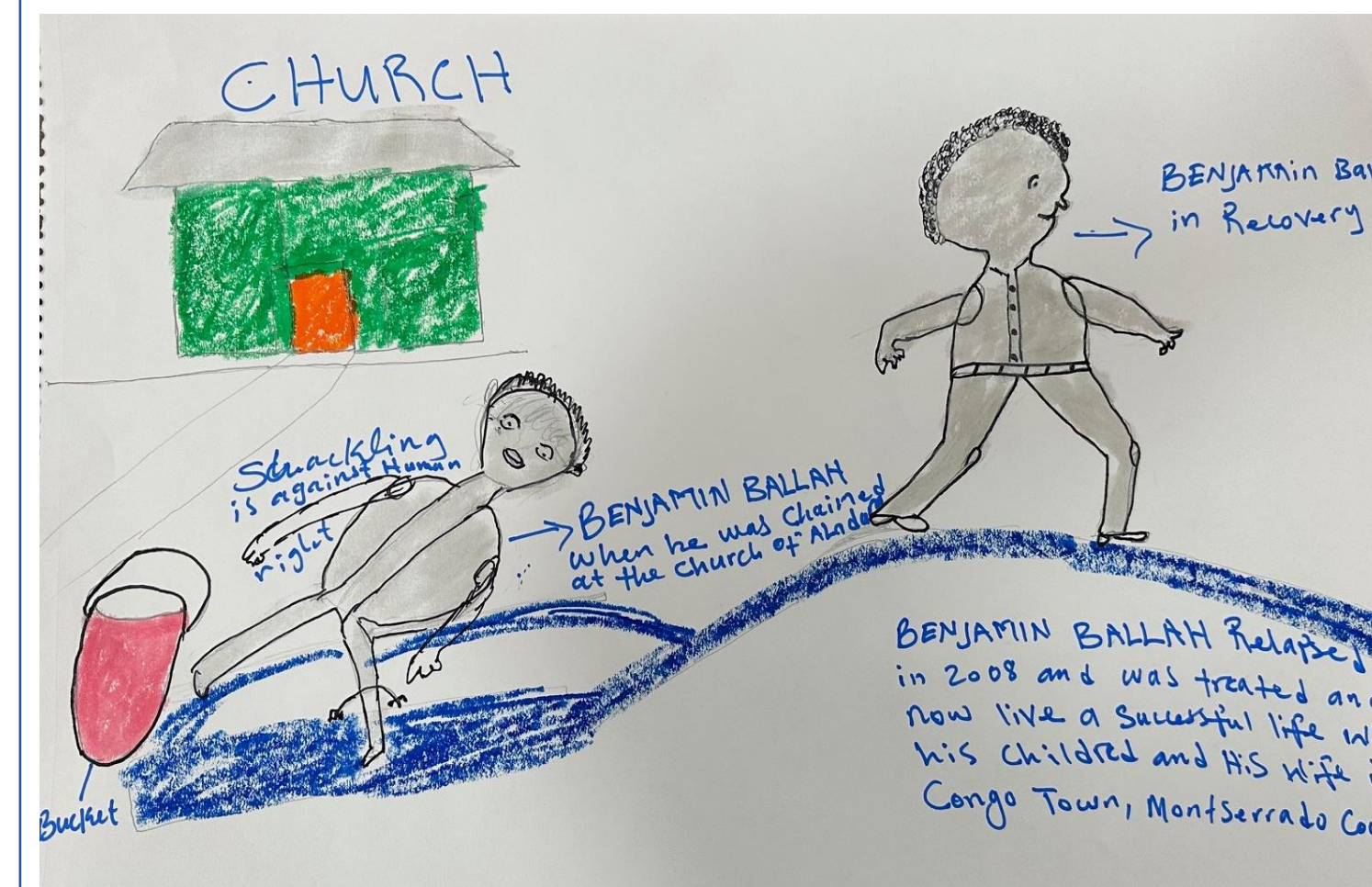


Illustration of man being shackled to his road to recovery

- Many experienced violence, stigma and shackling
- Gender-based violence
- Discrimination at work and housing
- Abandonment

Role of Caregivers

"Yes it affects me because,... I didn't really used to sleep at that time because I was always thinking about her, also the fear that she shouldn't get back in the street..."

(Male, brother of sister with psychosocial disability, 68 years old, Margibi)

- Associated stigma
- Emotional burden & Responsibility
- Lack of support and knowledge on condition and how to help

Support, Hopes & Aspirations

"People with psychosocial disability have a part to play in society, they should not be overlooked"

(Female, 56 years old, bipolar disorder, Margibi)



Illustration of a bright yellow sun, family and church

- Family, friends & faith as sources of support
- Empowerment - knowledge & independence through livelihoods
- Nature & green spaces

Reflections

A multi-faceted approach required that addresses both individual needs and systemic challenges in health system

Recognise role of family & caregivers

Increase access to mental health services and reduce accessibility gap – informal and formal sector

Prioritize investments in mental health services & holistic care (participation in education & livelihoods)

Address stigma: culturally sensitive & inclusive care

Promote person-centered care: meaningful participation and co-production led by people with psychosocial disability

References

1. Drew, N., Funk, M., Tang, S., Lamichhane, J., Chávez, E., Katontoka, S., Pathare, S., Lewis, O., Gostin, L. and Saraceno, B., 2011. Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis. *The Lancet*, 378(9803), pp.1664-1675. 2. Ringland, K.E., Nicholas, J., Kornfield, R., Lattie, E.G., Mohr, D.C. and Reddy, M., 2019, October. Understanding mental ill-health as psychosocial disability: Implications for assistive technology. In *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 156-170). 3. Mathias, K., Pant, H., Marella, M., Singh, L., Murthy, G.V.S. and Grills, N., 2018. Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India: a cross-sectional study. *BMJ open*, 8(2), p.e019443. 4. Liberia Institute of Statistics and Geo-Information Services (LISGIS). (2017). 2017 Population and Housing Census: Final Results. Monrovia. 5. Cooper, J.L., 2015. Mental health and psychosocial support in the face of Ebola in Liberia: the personal and professional intersect. *Intervention*, 13(1), pp.49-57.